

# Submission to the Senate Inquiry Into the CSTDA

8<sup>th</sup> August 2006

My granddaughter is 21.

She was born with a moderate/severe intellectual disability and autism.

She is the subject of much love, but also much frustration.

She can be beautiful, winning, joyful, but she also has a dark side.

Sadly her parents separated while she was an infant, but they decided to share the care role, to allow a positive input from both parents, to share the extra load of her care.

When she was in primary school my granddaughters and my daughters life was torn apart with a therapist hurling abuse allegations at her father.

Although later to be proved malicious, docs (NSW) treatment of both my daughter and her ex-husband was disgraceful.

They hounded and harassed, accused with unrelenting ferocity both parents of unspeakable things, even though the sentence my granddaughter was 'supposedly said to have said' was impossible, given lack of language skills, her mono-sibylic ability to communicate. Even though her educators/school at this time also insisted to the dept that it was impossible for her to articulate with such complexity, they were determined to proceed with the allegations.

After a long ordeal with psychiatrists etc the conclusion was of a well-adjusted child, given her limitations and a caring, loving relationship with both parents.

Never the less over this period of time they managed to totally destroy the entire family dynamic.

The relationship was never to be the same again between the parents, and the relationship was to be difficult for all their children as their father had lost his spontaneity, and had become emotionally distanced, fearful of physical interaction.

He felt he could no longer care for her as she could not bathe and dress herself.

My daughter was left as the sole carer for my granddaughter, with no emotional support from her ex-husband, the shared care never again happened.

The years ticked by, life was difficult; my daughter was accessing pathetic little respite care, and struggled financially and emotionally.

One day my daughter picked my granddaughter up from her special school and she was acting strangely, she assumed she was coming down with something; she was vomiting, and put her to bed.

The next months were harrowing, my granddaughter totally withdrew, she dropped an enormous amount of weight in short time, she went from being a loving open and joyful person to a withdrawn, fearful angry person, who refused to leave the immediate grounds of her house.

If on the odd occasion my daughter could get her into the car she would cover herself with a blanket.

My daughter called her local services office to beg for help, she said that she believed her daughter had been interfered with; she was showing every classic symptom.

She called and called and called over a period of weeks, always with the promise that someone would get back to her.

No one did.

She rang the health services, said she believed her daughter had been assaulted, she was desperate, she needed the assistance of a therapist. She explained the reaction, she said my granddaughter had a disability.

She was asked what was the disability, and when she responded, she was told that they had just had an intake meeting; the next one would be in 3 months!

Could she contact them at a later date!

*We were later to find out that sexual assault has priority, we can only assume sexual assault of a person with intellectual disabilities does not.*

We found a private therapist who over time was of great assistance, but the cost was \$180.00 per visit, which for a carer without the possibility of employment was enormous.

It took 4 1/2 months of intense therapy, all carried through by my daughter with no supports to get to the stage of being able to return to a new school.

At the time of returning to school (5 months after the first call) the dept finally contacted her for EMERGENCY SUPPORT!

I believe if we could see the file, my daughter's reaction to the worker would be written up as difficult and extremely abusive.

My granddaughter has never really recovered, nor has my daughter; who lost heart, lost her own sense of strength; she became depressed and still struggles intermittently with massive depression.

The years have passed; my granddaughter has now also developed a mental illness, she lost her coping mechanisms and her comfort zones which I believe was contributed by lack of immediate support when she was assaulted, the neglect by government has yet again coursed through my daughters life.

There seem to be no supports at all for people with intellectual disabilities and mental illness. We were told my granddaughter could attend a day program for people with mental illness, but these programs are run with few staff.

My daughter thinks that would be endangerment, leaving my granddaughter with minimal support staff with mentally ill people who do not have intellectual disabilities.

Once more my daughter is left to struggle alone and in isolation.

She has been on a waiting list for support for my granddaughter's behavioural difficulties associated with the mental illness for nearly a year and a half.

How do you expect people to care and support their children and adults with disabilities with so little support?

It would seem that we put both the carer and the person with disabilities into the trash heap from the moment they are diagnosed.

Is this the best we can do?

Happily destroy families over nothing, but when something really happens ignore the pleas for help?

Respite services are so pathetic and far between, I, at 74 am the sole giver of respite care.

She has not had any funded respite for years.

It really came home to me how outrageous the system of support is in this country of ours when I became ill with pneumonia.

Enough could not be done for me, home care, home nursing visits, food deliveries, etc, yet my poor darling daughter struggles with no supports no help, nothing and it has been years of just that... nothing.

I have been thinking back to the supports put in place for my own mother, who died around the time of my granddaughters assault, the services were brilliant, they considered the needs of myself and my sisters while caring for my mother.

The in home supports were really terrific, as was the government funded retirement complex she lived in for years before she was hospitalised.

Our role was of keeping the mother/daughter relationship going, caring minimally, the odd shopping trip for underwear and the like, visiting with special food and flowers, the same as my children do for me.

Every support she needed was in place.

We fought for nothing, the social worker arranged everything, when she needed a different support, and it just seemed to us to appear!

My mother was very ill in the last year of her life and had to have full time nursing care.

The level of care she received was the best, the nursing home could not do enough for her and allowed the transition to full time care to be non stressful nor guilt ridden one for myself, my sisters and brother.

Why is it then that my daughter and other women who have disabled children get nothing without an absolute bunfight, and even then, the support is pretty under-whelming?

My mother's needs prior to the last year of her life, were far less than my granddaughters, have ever been, for my mother everything, but for my granddaughter, practically nothing...

I dread dying and leaving my daughter totally alone with this, it would seem to me, when I am gone, she will have no anchor of support at all.

I am a volunteer telephone councillor, I hear the tales of lack of help, of people believing their life is not worth living, and I see and know what they mean.

I have seen it in my daughter's eyes, in her body language at times of great stress.

I fear for her, and I fear for my granddaughter.

I fear that my daughter's entire life will be spent struggling with the care of my granddaughter, living on the edge of society, all alone.

As her mother I would love for my daughter to go on into her life and have another relationship, so she can enjoy the companionship of another.

If the past 20 years are a judge this will be highly unlikely, how will she meet someone when never given the opportunity to go out, to be free to pursue outside interests, without planning far in advance?

Her life cannot have any spontaneity, and spontaneity is the spice of life, along side freedom.

How many people are searching for a partner so encumbered, with the knowledge that the 24-hour care will be unrelenting?

I weep for my daughter and all those out there who society has just discarded in such a monstrous way, simply because they drew a short straw.

I weep for my granddaughter, because even though so dearly loved, she cannot be anything but a burden, as we do not allow her the supports to have a life away from her mother, a life pursuing her own peer friendships so that she is exactly what every other child hopefully is to their parents - a much loved pleasure.

Our adult children's lives should be woven into the tapestry of our lives, not be the entire fabric.

I beg of you, please do something for these families and the beloved children that need so much care, support and love.

Mother and grandmother.